SYNOPSIS

HIV RELATED STIGMA IN THE LIVES OF PERSONS LIVING WITH HIV AND THE IMPACT OF SEXUAL HEALTH EDUCATION IN REDUCING STIGMATISING ATTITUDES AMONG MIGRANT WOMEN IN THE TEA PLANTATIONS OF THE NILGIRIS

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SYNOPSIS

HIV RELATED STIGMA IN THE LIVES OF PERSONS LIVING WITH HIV (PLHIVs) AND THE IMPACT OF SEXUAL HEALTH EDUCATION (SHE) IN REDUCING STIGMATISING ATTITUDES AMONG MIGRANT WOMEN IN THE TEA PLANTATIONS OF THE NILGIRIS

Health is a vital factor in human development. A healthy human being contributes to the nation's productivity both quantitatively and qualitatively (Jain, 2010).Human Immunodeficiency Virus (HIV) infection and Acquired Immuno Deficiency Syndrome (AIDS) is a serious health challenge, and has become a critical threat to the survival of human beings. Furthermore HIV/AIDS, often strikes people during their most productive years and reverses human development achievements (UNDP, 2009).Consequently HIV, the virus that causes AIDS, has become one of the world's most serious health and development challenges

HIV is everywhere, but the intensity of the spread of the virus varies. Since the first case of HIV reported in 1981, more than 33.4 million people are currently living with HIV, globally. In India 2.4 million people are living with HIV (www.kff.org). Indeed, India, has a much lower HIV prevalence, less than 1%, but with a billion-strong population has the second highest number of HIV-positive people (UNAIDS,2010).Tamil Nadu, one of the hardest hit states of India, is home to 2.5 lakh people living with HIV (TN-FORCES, 2010).

Worldwide, people living or associated with HIV and AIDS are subject to stigma and discrimination. They may lose their employment and livelihoods, property, social status, children and friends. They may be given substandard care or even refused care at health centres. Stigma refers to the beliefs and attitudes that deeply discredit a person or group because of an association with HIV. This leads to discrimination-actions or omissions that harm or deny services or entitlements to stigmatised individuals (DFID, 2007).

Stigma is harmful, both in itself, as it can lead to feelings of shame, guilt and isolation of people living with HIV, and also induce negative thoughts which often lead individuals to do things, or omit to do things, that harm others or deny them services or entitlements (UNAIDS, 2003).

Stigma and its psychosocial consequences cause indescribable suffering to those who are stigmatised (Brakel, 2005). Especially, people living with HIV have been rejected by their loved ones and their communities, unfairly treated in the workplace, and denied access to education and health services – this holds true for the industrialised as well as the developing nations (Smart, 2004). In India, as elsewhere in the world, PLHIVs face stigma and discrimination in a variety of contexts, including the household, community, workplace, and health care setting (Population Council, 2006).

Stigma that manifests itself externally or internally may have different effects. External stigma may include the experience of domination, oppression, the exercise of power or control, harassment, categorising, accusation, punishment, blame, exclusion, ridicule, or resentment. It may sometimes lead to violence against a person living with HIV/AIDS.

Internal stigma (felt or imagined stigma) is the shame associated with HIV/AIDS and PLHIVs' fear of being discriminated. Internal stigma is a powerful survival mechanism to protect oneself from enacted or external stigma and often results in the refusal or reluctance to disclose HIV status or the denial of HIV/AIDS and unwillingness to seek help (The POLICY Project, 2003). Evidence suggests that internal stigma may aggravate psychiatric morbidity among PLHIVs (WHO, 2009).

The present study was an endeavour to analyse the internal as well as the external stigma that exists among the migrant women tea plantation workers in the Nilgiris.The study was conducted among the migrant women tea plantation workers owing to the following reasons:

The district of Nilgiris is popularly known as the queen of hills in India and is at an elevation of 700 to 1200 meters above sea level. Tea is the main source of income and it shapes the landscape of the district (Hani *et al.,* 2009). In the Nilgiris generally tea plantations are situated in remote and isolated rural areas (www.iuf.org). In the tea industry, 51 per cent of the workforce is women and a majority of them are employed to pluck tea leaves – the most labour-intensive

part of tea production (Goddard, 2005). Lack of education, poverty, social awareness, under employment and other similar drawbacks still haunt the majority of the working women in the tea industry and they become victims of HIV (Mousumi and Sekar, 2008).

An important source of HIV related vulnerability is mobility and migration, mobility being defined as a change of location and migration defined as a change of residence (NACO, 2007). Nilgiris is one among the seven districts having net positive migration in Tamil Nadu and plantation workers constitute the largest proportion of the migrants (Pranesh, 2005). Poverty, diminishing choices, denial of rights, and lack of access to information and services make migrant populations particularly vulnerable to HIV/AIDS (Mishra *et al.,* 2004).

Female migrant workers in particular are more prone to HIV as they are employed in relatively unskilled jobs often without legal status and little access to health services. They are often susceptible to exploitation and physical and sexual abuse. Women left behind by their spouses, due to their family's economic challenges, may be forced to exchange sex for food or money and thus become vulnerable to HIV. They may also be at risk if their husband returns infected with HIV (UNAIDS, 2008).

Additionally, the stigma and discrimination faced by the PLHIVs in the tea plantation makes their life more miserable. Therefore, it becomes, necessary to address the problem of HIV/AIDS related stigma and discrimination among the tea plantation workers of the Nilgiris district. Addressing the issue of stigma and discrimination has been predicted as a major step to minimise the effects of HIV/AIDS.

HIV/AIDS-related stigma comes from a powerful combination of fear and shame. Lack of understanding of the disease, misconceptions about HIV transmission and lack of knowledge of protection may trigger stigmatisation (Yang *et al.,* 2007). Negative responses and attitudes towards PLHIVs are strongly linked to general levels of knowledge about AIDS and HIV and, in particular, to the causes of AIDS and routes of HIV transmission (Bharat, 2001).

Low HIV awareness and high stigma, seasonal migration and gender inequity created the necessity to implement HIV education program in the selected area. Education on HIV related stigma can be used to change people's attitudes, values, beliefs and behaviours thereby enabling/helping them to have a proper,

non-stigmatising attitude towards HIV/AIDS and PLHIVs. Their behaviour then becomes supportive, sensitive and caring rather than stigmatising and discriminatory.

Most of the related research focuses either on individualistic experiences or on the broader community settings in which the root causes of stigma are grounded. The present study attempts to bring out the individualistic experiences of the PLHIVs as well as evaluate the impact of Sexual Health Education (SHE) in reducing HIV related stigma in the community to which the PLHIVs belong.

The general aim of this study, therefore, was to find out the role of sexual health education in reducing external stigma that persists in the community which in turn can reduce the effects of internal stigma felt by PLHIVs. The specific objectives associated to this study were to:

- reveal the HIV/AIDS scenario and HIV related services in the Nilgiris
- measure the existence of internal stigma among the persons living with HIV(PLHIVs) in relation to their knowledge
- elicit the effects of HIV related stigma on the quality of life of PLHIVs
- trace the causes and manifestations of external stigma among the migrant women tea plantation workers with regard to their knowledge
- develop a suitable training module on Sexual Health Education (SHE) focusing on HIV related stigma
- provide SHE to the selected migrant women tea plantation workers in their workplace and
- assess the efficacy of SHE in reducing HIV related stigma

The investigator executed cross sectional descriptive method in conducting the study. Both qualitative and quantitative research methods were used in the study. The study was conducted in three phases. The first phase elicited the effects of HIV related stigma in the life of persons living with HIV (PLHIVs), the second phase brought out the HIV related knowledge and attitudes of selected migrant women tea plantation workers towards PLHIVs and the third phase assessed the efficacy of SHE in reducing HIV related external stigma among the selected migrant women tea plantation workers.

In the present study, the District of Nilgiris was selected as the study site for following reasons: The existence of more number of migrants and the high

risk behaviours associated with the living conditions of the migrant women tea plantation workers and the high prevalence rate of HIV in the Nilgiris initiated the investigator to conduct the study.

In Phase I and II, all the four blocks of the Nilgiris namely Coonoor, Kotagiri, Gudalur and Udhagamandalam were selected to conduct the study. Based on accessibility and familiarity of the investigator, Glendale Estate in Coonoor Block was selected to impart Sexual Health Education (SHE) to the selected migrant women tea plantation workers in Phase III.

In any HIV related stigma research, three key populations are highlighted: they are Persons Living with HIV (PLHIVs), Health Care Workers and General / key populations at higher risk of HIV. Triangulating data by including more than one of these populations as participants in a study is a way to get a more complete picture of stigma from multiple perspectives (WHO, 2009).

In Phase I, thirty four health care workers/key informants were selected to gather information related to HIV/AIDS scenario in the Nilgiris by using the key informant interview guide. Key informant interviews are qualitative in-depth interviews with people who know what is going on in the community. The purpose of key informant interviews is to collect information from a wide range of people - including community leaders, professionals, or residents who have first-hand knowledge about the community. These community experts, with their particular knowledge and understanding, can provide insight on the nature of problems and give recommendations for solutions (UCLA - Center for Health Policy Research, 2004). Hence the information related to policies, programmes and services available for PLHIVs in the District was obtained from the key informants.

Along with the key informants, 180 PLHIVs (125 female and 55 male) were selected through purposive sampling method. To elicit the effects of internal stigma qualitative methods such as Focus Group Discussions (FGDs) and case studies were used. For FGDs, 47 PLHIVs (11 male and 36 female) were selected with their consent and 16 PLHIVs accepted to share their life experiences for in-depth case study analysis.

Totally four FGDs were conducted with an aim to bring out the effects of HIV related stigma. FGD is more than question-answer interaction wherein the members are also encouraged to discuss the topic among them. The stigma

related experiences of PLHIVs were brought out in the contexts of policy and legal issues, family and community, work place, school and in the institutional context (Hospitals).

To measure the existence of internal stigma in relation to HIV related knowledge, Berger Stigma Scale was used along with a knowledge assessment tool. The knowledge assessment tool consists of 15 dichotomised statements on HIV/AIDS and measures the knowledge score of PLHIVs on HIV/AIDS. The 40-item HIV Stigma Scale developed by Berger et al. (2001) measures stigma perceived and experienced by PLHIV. The items are formulated as statement and responses are given on a 4-point agreement scale. The psychometric properties of the scale have been tested in a large sample of diverse background. Apparent overlap between items and the high alpha coefficient (0.96) suggest that the instrument could perhaps be shortened without loosing validity.

The Berger Stigma Scale is considered to be one of the best methods to measure internal stigma (Brakel, 2005).Internal stigma is assessed on four domains viz. Disclosure concerns, Negative self image, Public attitudes and Personalised stigma. For statistical analysis, the total internal stigma score was taken as the dependent variable and each domain score as independent variable.

In Phase II, 1000 migrant women tea plantation workers, the general/key populations of the Nilgiris, from all the four blocks (Coonoor-285; Kotagiri-220; Gudalur-225; and Udhagamandalam- 270) were interviewed to bring out the existence and manifestations of external stigma towards PLHIVs with regard to their knowledge on HIV/AIDS.

The questions related to respondents' socio - economic status in the Interview schedule, revealed their marital status, occupation, type and composition of family, living conditions and working status etc. The existence of external stigma was revealed through 77 statements rated on a 3 point scale. After careful analysis, these 77 statements have been divided into seven domains such as fear, misconceptions, attitudes about personal contact, blame and judgmental attitudes, social withdrawal, denial of rights and loss of access to resource and livelihoods.

To assess the knowledge level of the migrant women tea plantation workers on HIV, 20 questions were framed. At this juncture, external stigma score and knowledge score were considered as dependent variables and the seven domain scores as independent variables for statistical analysis.

In Phase III, two hundred and forty five migrant women tea plantation workers were chosen for the sexual health education program in the Glendale Estate for 28 days.The investigator made an effort to see that all the women selected for the SHE programme were comfortable and understand the subject. Special care was taken to check that the span of attention is sustained throughout the programme .This was possible because of different interactions made with them through informal education.

Various participatory and non participatory methods such as lecture, role play, demonstration, exhibition, group discussion and performing folk arts and street play were used in SHE to initiate changes in the attitudes of the sample. The need for a training module to implement SHE was realised by the investigator and the same was developed and used in this study. The efficacy of SHE in reducing external stigma was analysed statistically.

As HIV/AIDS is considered as a highly stigmatised issue care had been taken to maintain the confidentiality of the information obtained. The ethical considerations in conducting such research were also followed carefully.

Quantitative data were analysed by using SPSS Package Version 11. The data obtained was consolidated, tabulated and subjected to statistical analysis. Qualitative data which were collected through focus group discussions and case studies with the help of a moderator are also presented in the study.

The key findings pertaining to the present study are given below.

- In the Nilgiris the prevalence of HIV showed an increasing trend. The data gathered through the key informants revealed that in 2003, the number of PLHIVs in the Nilgiris was 29, while in the year 2010, it rose to 679.
- HIV related stigma either internal or external was found to be pervasive and negatively impacts the quality of life of people living with HIV.
- The experience shared by the PLHIVs through focus group discussions and case studies revealed the existence of HIV related stigma in the Nilgiris. The qualitative data obtained in this study substantiate the

stigmatising and discriminatory activities such as denial of house for rent, denial of property and marital conflicts etc. Also the Internal and external stigma was an impediment to access treatment and care services and in adherence to treatment.

- The present study measured the HIV related internal stigma in a sample of 180 PLHIVs in the Nilgiris. Majority of the respondents (90 per cent) were below 44 years. Sixty Seven per cent of the respondents were engaged in tea plantation work and some of them (14 per cent) were not working due to their deteriorating health condition. Those who worked in the tea plantations earned ₹ 1000-2500 per month.
- In the view of PLHIVs, the reasons for stigma and discriminatory practices were found to be due to the fear of infection (55 per cent) and wrong attitudes (45 per cent) about the HIV victims. Questioning on the ways to reduce stigma, all the PLHIVs unanimously suggested education as the key to reduce HIV related stigma.
- The explicit focus in the present study on the consistent relationship between gender and internal stigma scores indicate that there was no gender difference in the measurement of internal stigma experienced by PLHIVs.
- A comparison of men and women with reference to the quantum of stigma they possess has been carried out. The student's "t" test of significance has been instituted to test the mean difference between men and women. The "t" statistic has been 1.97 which is a non- significant value. From this, it is implied that the overall stigma score have been the same establishing that the gender has no role to play in explaining the magnitude of internal stigma score that may be with men or women.
- The relationship between the internal stigma score and the knowledge score was brought out using statistical analysis. The results revealed that internal stigma score will decrease by about 1.6745 units for every one unit increase in the knowledge score.
- The socio - economic status of the selected migrant women tea plantation workers was also very poor. They depended solely on the daily wages which was very meager for their family living.

- The simple correlation co-efficient to assess the relationship between the external stigma score and the seven domain scores revealed that the external stigma has significant relationship with all the seven domain score excepting the “Denial of Rights” domain.
- The impact of SHE imparted to 245 migrant women tea plantation workers was found to be effective. After imparting SHE, there was a remarkable change in the external stigma score. Considering the reduction in the external stigma score, it can be concluded that SHE helped the tea plantation workers in changing their stigmatising attitudes towards PLHIVs.

Stigma is social phenomenon so it needs to be addressed at both individual and social level. The results presented above clearly narrate the stigmatised and discriminatory experiences of PLHIVs at individual level. It is evident from the study that suitable education programme can bring positive attitudes at the community level and can bring changes in the lives of people living with HIV/AIDS.

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